

PRESS RELEASE FOR IMMEDIATE RELEASE

New research provides evidence to improve health of people with Down syndrome

Results from one of the first studies to examine the full lifespan of people living with Down syndrome have been [published](#) in The Lancet medical journal, providing evidence in support of health guidelines specifically for people with the condition. Recommendations from the study include medical assessment at the optimum time to prevent ill health and improve health outcomes for the group, enabling them to live healthier and longer lives than ever before. Previous studies have focussed on either adults or children with Down syndrome.

The study by the European [GO-DS21 consortium](#) utilised the UK Clinical Practise Research Datalink (CPRD) GOLD database to compare the health information of more than ten thousand people with Down syndrome to that of the general population and those with intellectual (or learning) disabilities to identify patterns around thirty-two health conditions associated with Down syndrome. CRPD GOLD is one of the world's largest sets of longitudinal routinely-collected electronic health records collected from UK primary care practices.

Notably, the GO-DS21 consortium highlights that the ground breaking Down Syndrome Act 2022 recognises the need for specialised services and support to help improve life for individuals with Down syndrome and that their study results support that call.

The National Down Syndrome Policy Group has raised concerns about consistently poorer health experiences and outcomes for people with Down syndrome and worked with Dr Liam Fox MP to create the Down Syndrome Act 2022 which became law in April 2022 with the aim of ensuring that health, social care, education and other local authority services take account of the specific needs of people with Down syndrome when commissioning or providing services. The Act requires the Secretary of State to publish guidance for relevant authorities (for example, NHS hospitals or local councils) on the steps it would be appropriate for those authorities to take to meet these specific needs when carrying out some of their most important functions. Once the guidance is published these authorities are legally required to take the guidance into account when providing certain core services. It is hoped that identifying patterns in health issues more prevalent in those with Down syndrome, will help inform this guidance and practice and lead to better outcomes for these individuals.

Necessary guidance for the Down Syndrome Act which will apply only in England is expected later this year and will include guidance around health matters.

During a World Down Syndrome Day debate on Down syndrome which took place in the House of Commons on 23rd March this year, Scottish SNP MP Chris Stephens spoke movingly about how 'diagnostic overshadowing' in health circles left one of his young constituents who has Down syndrome in chronic pain and bleeding for two years resulting in 'irreversible damage'. He described Scottish Government legislation proposals for a wider learning disability Bill and how he would like to see Down syndrome included in the title of the Scottish Bill due to the specific issues faced by the group.

BACKGROUND

Life expectancy for people with Down syndrome has increased dramatically over the last 80 years or so yet people with the condition still [die at an earlier age](#) than people in the general

population and those with intellectual disabilities meaning that there is opportunity to improve health outcomes for this minority.

Whilst we know that people with Down syndrome are at a higher risk of developing certain health conditions there is little research to show the patterns of occurrence and the relations between the conditions. The Go-Ds21 Consortium research provides evidence to show that people with Down syndrome have much higher rates of dementia, epilepsy, thyroid issues and sleep apnoea compared to the general population and also those with learning disabilities who don't have Down syndrome. They have also been able to determine the age that people with Down syndrome develop the conditions which can differ from other people thus contributing evidence to the case for Down syndrome specific health screening and monitoring. Knowing all these facts can help with the prevention and management of health issues.

Conversely, the researchers found that people with Down syndrome are less likely to develop high cholesterol, high blood pressure, solid cancers or mental health disorders compared to both the general public and those with learning disabilities.

GO-DS21 Consortium say that to achieve better health outcomes, people with Down syndrome *"may require access to specialised expertise and support as recognised in the new Down Syndrome Act."*

The National Down Syndrome Policy Group is a UK based group of people with and without Down syndrome which was established in 2020 in an effort to raise the profile of the unmet needs of people living with Down syndrome.

Tommy Jessop, author, first actor with Down syndrome on prime-time TV, star of BBC's Line of Duty crime drama and National Down Syndrome Policy Group Ambassador says:

"Good news that we are living longer, healthier lives and we don't get certain cancers.

I welcome this research which helps medical professionals understand how to look after our healthcare, help us live healthier lives and prevent ill health, like they help other people. It is really helpful to us.

I think we need even more research into which foods are healthy for us and taking more exercise.

Then we will be healthier and able to live our lives to the full and be fulfilled."

Dr Elizabeth Corcoran, Chair of Down Syndrome Research Foundation UK and a founding member of the National Down Syndrome Policy Group says:

"Children and adults with Down syndrome have been known to have unique health challenges for many years. This research confirms the health complexities facing people with DS and their carers as they navigate the health system to have their health needs met, frequently falling between the cracks. The consequences of offering a 'one size fits all' medicine for those with Learning disabilities can be easy to see from this data. People with DS have unique health differences that need to be acknowledged, anticipated and treated in a timely manner. Living longer means living better too. We want that for everyone don't we?"

Peter Brackett, Chair of the NDSPG says:

“This research is timely as the guidance for the Down Syndrome Act is currently in development. The National Down Syndrome Policy Group and our members hope that comprehensive guidance fully conversant with the relevant research and experiences will take us closer to a time when specialist health services will help ensure that people with Down syndrome can receive better healthcare and live, longer healthier lives.”

ENDS

- For more information, see the National Down Syndrome Policy Group website www.ndspg.org or email contact@ndspg.org
- For interviews contact:
 - -Dr Elizabeth Corcoran on 07956499976 or email Elizabeth.corcoran@ndspg.org
 - -Ken & Rachael Ross MBE on 07710 612 807 or email ken.ross@ndspg.org rachael.ross@ndspg.org
 - -Peter Brackett on 07515 121733 or email peter.brackett@ndspg.org
- The Lancet publication on Multiple morbidity across the lifespan of people with Down syndrome or intellectual disabilities [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(23\)00057-9/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(23)00057-9/fulltext)
- Authors’ Lay Summary of the research Multiple morbidity across the lifespan in people with Down syndrome <http://bit.ly/DSLANCET23>
- Down Syndrome Act <https://www.legislation.gov.uk/ukpga/2022/18/enacted>
- SNP MP Chris Stephens speaks in House of Commons Down syndrome debate <https://www.youtube.com/watch?v=92tW tdKJMq>
- ‘Historic’ moment as support for people with Down’s syndrome written into law <https://www.telegraph.co.uk/news/2022/04/01/downs-syndrome-guidance-given-councils-hospitals-historic-new/>
- People with Down syndrome who are trustees of the Down Syndrome Policy Group welcome the introduction of the Down Syndrome Bill: [Launch of The Down Syndrome Bill - YouTube](#)
- ‘It’s time for us to live our lives to the full’: Line of Duty’s Tommy Jessop on changing the world for people with Down’s syndrome <https://www.theguardian.com/society/2022/feb/02/its-time-for-us-to-live-our-lives-to-the-full-line-of-dutys-tommy-jessop-on-changing-the-world-for-people-with-downs-syndrome>